

### *Occasional reports*

## Managing radical surgery: notes from the patient's viewpoint

**SUMMARY** Based on a diary which was kept while preparing for and undergoing panproctocolectomy, the paper describes the process of coming to terms with an ileostomy. A number of stages in the process are identified: anticipation, reorientation, trauma, maintenance of selfimage and accommodation. The social-psychological strategies for coping with the process are elaborated.

This is an autobiographical account which describes becoming an ileostomist. The paper is based on a diary, started after the recommendation for surgery was made. The reasons I decided to keep a record of my experience were part professional and part therapeutic. By training I am a social scientist with a professional interest in applying sociological and psychological ideas to medical matters. For a number of years I had taught nursing students about the social-psychological aspects of health and illness. My experience was therefore an opportunity to gather background information at first hand. As the months went by, however, keeping a diary became an important outlet for my feelings, emotions and frustrations, a kind of self-therapy. Of course, the account is therefore highly subjective and should be read as such.

When surgery was advised I had had medically diagnosed ulcerative colitis for 19 years. I was 30 years old, and my wife was expecting our first child. I had until then lived with the disease, without it interfering with my social functioning very much. I shall begin at the point when I learned that dysplastic features were evident in my bowel.

### **Anticipation**

The recommendation for total colectomy was not a surprise. I had known for many years about the long term complications of even mild ulcerative colitis and about the likelihood of major surgery. This is not to say I was not upset. But I was also rather relieved in an odd way, that the long expected bad news had finally materialised.

Two weeks later I consulted a surgeon. He was rather vague about postoperative life and explained that a counsellor would answer any questions I had. He did encourage me to trust to his medical judgment and surgical expertise however. I went along with this and decided after some equivocation, to have the operation. Reassurance about surgical matters did not, unfortunately, alleviate my growing worries about my post-operative life. My fears focussed on what I took to be the stigmatising

nature of having an ileostomy. I responded to the anxiety in two ways: verbal role distance and selfreproach. By verbal role-distance I mean that when I discussed my impending operation or wrote in my diary, I would do so, as if the events were not actually happening to me. But I was also both despondent and angry because of what I regarded as a kind of personal failure. The selfreproach and disgust I felt, added to my inner sense of gloom. Externally, however, I tried to appear cheerful.

### **Reorientation**

I brooded and my feelings alternated between acceptance and selfhate. It was in this mood that I met the ostomy counsellor, a representative of one of the appliance manufacturers. She was an ileostomist herself. She offered reassurance and answered my questions. She appeared to understand exactly how I was feeling and to empathise with me. Her knowledge about postoperative life seemed encyclopaedic. Functionally our meeting was highly successful. I felt relieved. I was better prepared for and, more importantly, reconciled to the surgery. I now had some idea about what to expect. Beyond the functional level, however, a number of other things occurred at that meeting. Although I did not fully realise it at the time, these were to be extremely important to me. Effective acceptance of being an ileostomist involves changing the potential and actual ileostomist's view of their situation. In particular the idea, that being permanently incontinent and of wearing a bag, is the end of normal life, must be confronted.

The counsellor I met, set out to overturn the idea that having an ileostomy was odd, or stigmatising. Instead she defined the condition as a non-problem. She emphasised the fact that most people feel much better postoperatively. Her aim was to get me to accept that which I had previously found unacceptable. I was doubtful, but she provided me with a new and positive framework within which I could think about my experience and anticipate the future. From the prospective ileostomist's standpoint, the prognosis of ulcerative colitis is pretty certain and the detail of what undergoing surgery will involve, in the sense of where the incisions will be, and approximate time in hospital, can be easily ascertained. What is extremely unclear is what life as an ileostomist will be like. The uncertainty may create emotional problems. Interestingly, the work of dealing with such anxieties is sometimes done by lay counsellors. It seemed to me then, and it seems to me now, that this is not just a case of lay persons helping the professionals. In the final analysis lay persons, who are ileostomists, may be used as ideal role models of successful postoperative adjustment, in order to persuade the patient of the advantages of the operation. This has the consequence, perhaps unintended, that the doctor is absolved from the ultimate responsibility of, and therefore blame for, making the decision which leads to bodily mutilation.

After my meeting with the counsellor, I began to orient myself to the realities of my situation. I developed a number of strategies to address what was happening to me. First I devised a rationalisation in which I saw myself as fortunate for two reasons: the danger signs of cancer had been diagnosed early and I had never had any significant problem, until then, with the ulcerative colitis.

Second, I came to accept the medical opinion that I needed surgery. My

acceptance of the medical definition was a gradual process. At first it was highly instrumental and manipulative, not least to achieve some of the secondary gains of the sick role.<sup>1</sup> I acted out the role of a gritty fighter against disease, but as the time for the operation drew nearer and I became more worried about it, I stopped consciously presenting a front and began to see myself as a sick person. This was quite a change in thinking for me, because in the 19 years I had had the disease, apart from the first attack, I had lived a near normal life. Indeed I had always thought of myself as a well person. Thinking of myself as sick, of course, made it easier for me to accept the ostomy counsellor's view that after surgery I would feel better. The more I accepted the medical opinion that I was sick, the more relief from anxiety I felt. It was as if by defining myself as an ill person, I was handing over responsibility for my disease to someone else. The more I thought like this, the fewer doubts about having the operation I entertained. It was in such a state of mind that I was admitted for my operation.

### **Surgery and trauma**

When I woke after surgery I was disorientated and experiencing extremes of hot and cold. It appeared that tubes and pipes came from all parts of my body. My only sensation was of euphoria, caused by pain killing injections.

For the next six days sleep was more or less all I did. Nurses fussed around me, but I took little notice. I was unconcerned by anything very much until a week after the operation. During the sixth postoperative night the appliance became detached and leaked. My stoma seemed to become very active and malodorous liquid poured out. The realisation that I had lost control of this aspect of my body function really only dawned on me at that moment. I lay there in a pool of foul smelling excreta without any clear idea of what to do. It was just about the time that the night shift were going off duty and it was sometime before help arrived. In due course a new appliance was fitted and my bed was changed. I was grief stricken however, and felt miserable and terribly depressed. The next 48 hours were wretched. The best efforts of staff and visitors to cheer me up just made me feel worse. As the days passed, the realities of my new body function became increasingly apparent. With each new leak and spillage and with the constant smell, I became more depressed. The presurgical counselling I had had, had neither prepared me for the psychological trauma of the postoperative phase nor for the realities of the way my body now worked. In retrospect, I doubt whether any amount of counselling could have helped me anticipate seeing my new stoma pouring forth liquid faeces. My experience was akin to one of loss. I also felt very concerned and unprepared for the unknown, but now expected difficulties. Once I left hospital I feared that the possession of a stoma would not only be a stigma, but would be the dominant element in my life. I was very concerned that I would be unable to live and cope with the way my body now functioned.

The physical state was not my only focus of attention. I was also very worried about the incontinence, the smell and consequent occasional nausea. These would, I thought, be the defining characteristics of my social identity. In the immediate postoperative period, when I had been attached to drips, tubes, and catheters, my new bag was just part of the postsurgical

paraphernalia. Once all but the bag were removed, it became the focus of my attention and I hated it.

### **Maintaining selfimage**

I thought that my identity as a man, as a whole person, was under attack. I was preoccupied with ideas of failure. In the face of these perceived threats to my sense of who and what I was, I attempted to hold on to my self-image. I did this in two ways. First I engaged in 'passing', 'normalising' and 'attenuating' behaviour. Second I tried to gain control over my prosthesis. By 'passing', I mean behaviour where I consciously tried to appear normal, to pass myself off as a non-ileostomist. This was, of course, impossible in hospital, when my reason for being there was *qua* ileostomist. It was quite easy, however, outside of hospital. 'Normalising' behaviour involved facing up to my ileostomy, accepting it as part of my normal identity – but recognising that what was normal for me was not normal for others. By 'attenuating', I mean behaviour in which I recognised the problems of the ileostomy but tried to minimise their effects.<sup>2-4</sup>

Initially I could not control my surgical appliance and neither could I master its technicalities. I was extremely suspicious of it; passing, normalising and attenuating were therefore out of the question. The bag seemed to develop leaks at unpredictable times. For the first couple of months after surgery it absorbed my attention. I worried about the bag becoming detached. I had opted to use an appliance which had to be changed every five days. In principle this is a very simple thing to do. In practice for the novice, it can be difficult, frustrating, and time consuming. Also in the first few weeks I felt sure everyone could see the bulge under my clothes.

I only began to feel better about the equipment when I became its master, rather than its servant, and I learned to relax with and trust it. This was a gradual process involving the acquisition of knowledge and the crucial turning point occurred when I realised I could be independent of the ostomy-fitter, and therefore enjoy some autonomy over my own body functions. I acquired the necessary knowledge by trial and error and with the fitter's help. Eventually I found a suitable range of components to fit together and wear, a process that took about two months. Increasing expertise allowed me to drain and change the appliance without fuss. The result was growing selfconfidence.

### **Accommodation**

Through the strategies mentioned, I preserved a continuing sense of who I was, but I still had to live with my ileostomy. Even if I did not fully accept it, I gradually accommodated to it. The process of accommodation had several aspects. First I came to view my preostomy life as one in which I was ill rather than well. Second, I defined life as an ostomist in positive terms. Third, I engaged in a process of rationalising about my condition.

In order to regard preostomy life as one in which I was unwell I had to reinterpret past events. Before I had my operation, I had denied and ignored any symptoms I experienced. I always explained feeling unwell to late nights, overwork, or overindulgence, never to the colitis. I

now attributed earlier illness episodes to the colitis. My view gained support on my first visit to the outpatient clinic, after my discharge. I asked about the histology of the removed colon. I was told that I had been on course to develop a tumour. This helped to justify all that I had been through.<sup>5</sup>

To define postoperative life in positive terms was relatively easy. I began to notice within about three weeks of the operation, that I was experiencing a sense of physical wellbeing which I had not felt for many years. Whatever the objective source of these feelings, I concluded that they were because of the absence of the disease. These feelings continued noticeably for several months and I genuinely felt as well as I had ever done, or could remember. The ileostomy seemed to be a relatively small price to pay for these experiences. I gradually joined in the normal round of social life and other activities. I said to myself, that apart from my incontinence, which was now manageable, my biological and social functioning was not only unimpaired but enhanced. My physical appearance seemed to have changed for the better, I had lost a lot of excess weight, my skin and hair looked to me to be in better condition than they had been for years, and perhaps above all, my ileostomy gave me a sense of freedom from the constant worry of the sudden attacks of diarrhoea. I now realised that what I had taken to be a normal life before my operation, had in fact been tightly circumscribed by my symptoms. I had just never really taken much notice of them. All of this made me feel good about myself and my life and compensated for some of the difficulties I encountered.

There were other aspects to this process. Meeting people became a source of pleasure. Friends and relatives who knew I had been in hospital said I looked well. People who did not know this appeared to be totally unaware of my physical state. I had been very worried that my bag would be conspicuous. In the event it was not, and my ileostomy remained secret. Privately I had to carefully organise my life. This was not new to me. Persons with ulcerative colitis, even in mild form, develop habitual planning strategies in regard to the presence of lavatories. My postoperative organisation involves making time and space (once every five days for about an hour or less) to change my appliance. I also keep spares at work, at home, and in my car.

A key aspect in my accommodation is the process of verbal rationalisation. This involves me acknowledging that I have a kind of deviant status, but that, all things considered, matters could have been worse. I have various repertoires for this. One is the idea that I have been fortunate. I never suffered very much with the ulcerative colitis. The symptoms I did experience I never seemed to worry about, and because the medical care was so expert, the disease never became the threat to my life that it could have been. Another repertoire is the idea that I have been lucky because the ileostomy does not prevent me doing my job (as a lecturer). Further, because lecturing is a middle class occupation with generous sick pay provision and because I was treated under the British National Health Service, there have been no economic costs incurred to me or to my family as a consequence of my disease and surgery. The final rationalisation is that I convince myself that I have done the right thing, as the alternative to having surgery would have been almost certain eventual death.

## Conclusion

I had initially worried that all my dealings with 'normals' would be conditioned by my ileostomy. In the event this worry was unfounded. Being an ileostomist is not a master status in the way I originally thought it would be.<sup>6</sup> It still affects my self-image, however, and going through the operation and the rehabilitation have been profound social experiences. In that sense, although I may accommodate very well to the ileostomy and others will not know of my condition, I still know I have it and my life and my attitudes to myself have been changed considerably. Having this operation has caused me to reflect long and hard about my life, and some things will never be quite the same for me again.

At the time of writing this paper it is over two years since my operation. I am active in the local division of the Ileostomy Association. I have also extended my professional interest and written about living with ulcerative colitis,<sup>7</sup> about physiotherapy after surgery<sup>8</sup> and about the trauma of the inpatient surgical experience.<sup>9</sup> Voluntary work and the writing have all helped me deal with the ileostomy at a personal psychological level. Medically I have had a few further problems. The rear wound has been very slow to heal. I have also had a couple of blockages and several bouts of diarrhoea which made me feel very ill.

Although this may sound slightly perverse, my work with the Ileostomy Association, my writing and the occasional medical problem aside, my ileostomy does not in fact intrude on my life very much. The social effects of being an ileostomist in the mid to long term are very different to those of the short term. At the time of my operation my ileostomy became my main focus of attention. It was, temporarily as it turned out, the single most important thing in my life. I thought, at that time, that it would remain so. Once I was able to get control over the appliances however, regain selfconfidence and get on with other aspects of my life, such as my work and family, the ileostomy became less and less salient.

The significance of this is probably two-fold. In the days immediately after surgery I never realised that the ileostomy would become less intrusive than it was then. Knowing that then might have helped. Also I was fortunate in so far as I have a very supportive family and I had a job to return to. My guess would be that for a new ileostomist who lacks social contacts in work or leisure or social support from family and friends, the ileostomy is likely to assume and maintain a very high profile indeed.

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M P KELLY

*Dundee College of Technology,  
Dundee.*

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